

**INDIANA GENETICS ADVISORY COMMITTEE**  
**MEETING MINUTES**  
**April 18, 2006**  
**12:00 –3:00 PM**  
**Indiana State Department of Health**



**ATTENDANCE:**

**Full Members**

**Ad-Hoc Members**

Abernathy, Mary Pell		Michalski, Scott		Barnet, Karen	X
Arnold, Jan	X	Moore, Marva	X	Bizzarri, Jaime	X
Bader, Patricia	X	Olsen, Donna Gore	X	Bowman, Bob	X
Bingle, Glen		Quaid, Kim		Conner, Joel	X
Brillhart, Julia		Rautenberg, Joe	X	Ganser, Judy	
Cohen, Stephanie	X	Reed, Terry	X	Long, Weilin	
Cushman, Lisa	X	Shutske, Krysta	X	Meade, Nancy	X
Darroca, Roberto	X	Smith, Lisa		Quintana, Carmen	
Downer, Dawn	X	Stevens, Melody		Schulte, Julie	X
Escobar, Luis		Stone, Kristyne		Schwandt, Kirstin	
Grover, Spencer	X	Torres, Wilfredo		Silva, Ruwanthi	X
Gulyas, John		Vaughn, Shelley		Smith-Bonds, Tasha	X
Hendrix, Jon		Wappner, Rebecca		Waller, Carolyn	X
Hodgin, P. T.	X	Weaver, David	X		
Kucharski, Ellen		Zaidi, Syed-Adeel	X		
Mendenhall, Gordon	X	Zunich, Jan	X		

Also in attendance were Stephanie Guron (in place of Dr. Wappner), Jennifer Shurn (in place of Shelley Vaughn), and Jeanne Darroca.

Julia Brillhart, Dr. Hendrix, Ellen Kucharski, Dr. Quaid, and Kristyne Stone forwarded their regrets.

After a lunch time talk, “Inherited Thrombophilia and Implications for Primary Care Physicians”, by Dr. Syed-Adel Zaidi from IU, Dr. Bader called the meeting to order. Attendees registered their attendance and received a packet of materials including all of the following:

- Meeting agenda for 4/18/06
- Meeting minutes for 10/11/05
- IGAC By-Laws, with changes that were approved at the October 2005 meeting
- IGAC membership directory
- ISDH Genomics and Newborn Screening Update
- ISDH Genomics Education Report
- Update on Indiana Folic Acid Campaign

- Region 4 Genetics Collaborative Update
- Information sheet about CMV
- IGAC subcommittee list

Dr. Bader opened the meeting with a welcome and introductions. Minutes from the October 11 meeting were approved.

Nancy Meade reported on the status of ISDH Genetics activities.

- Jaime Bizzarri started on March 16, 2006 as the Genomics Public Health Nutritionist.
- The Sickle Cell database is about 90% complete and should be linked to the Indiana Sickle Cell Coordination Projects in the near future. This will enable the Sickle Cell projects to begin to report quarterly as well as annually.
- The Indiana Birth Defects Problem registry has been modified to include audiologists as healthcare providers and ICD-9 codes associated with hearing loss. These changes will be effective by July 2006. The new performance measures for all Title V funded Genetics clinics require these clinics to report all children born with birth defects under the age of three to the Indiana Birth Defects and Problems Registry (IBDPR). Forms for reporting are now available online. The IBDPR staff is in the last stages of reviewing the educational materials and parent letters. These materials will be ready for mailing within a few weeks.

Karen Barnett spoke on the State Folic Acid and FASD Campaigns.

- She had been mailing out "TAKE IT, SERIOUSLY" information for the folic acid campaign. The campaign ends in May 2006, but there are many brochures and posters still available that can be utilized for the next few years.
- The FASD campaign is planning an initiative that "No baby shall be born in Indiana with Fetal Alcohol Spectrum Disorders." The result of the needs assessment will be completed by May 2006. Karen passed out a copy of the 2<sup>nd</sup> draft of the FASD to all IGAC member who desired it. The second draft is to be reviewed and returned with comments.

Karen also discussed the Genomics Education Report.

- The 4<sup>th</sup> issue of Transcription's, the genomics newsletter for Health Care Professionals is at the printers now and is expected to be out within the next 4-5 weeks. Requests for future articles for the 5<sup>th</sup> edition of Transcriptions was made by the editor.

Bob Bowman briefly discussed Region 4 activities including the upcoming meeting in Lansing, MI from October 17-19. There are accommodations for up to 10 people from each state. Individuals interested in attending the conference should contact Bob Bowman.

Issues requiring input from IGAC were then discussed.

- Bob Bowman initiated discussion by talking about Cystic Fibrosis Newborn Screening. On February 22, 2006, Dr. Phillip Farrell spoke at IUPUI about Cystic Fibrosis (CF) and Newborn Screening (NBS). The information gathered from that talk included: 22 states have implemented some form of CF Newborn Screening, the cost per child varies

depending on the type of testing implemented, the cost ranges from \$2.27 to \$3.55 per child, the benefits of including CF in the newborn screen are that it would prevent the death of the ~5% of undiagnosed patients and it would cost half as much to diagnosis by NBS versus the traditional method.

-Julie Schulte discussed CMV Newborn Screening. CMV is the most common virus transmitted from mother to unborn child. Congenital CMV can occur if a woman has a new CMV infection during pregnancy. Women who were previously infected (i.e. before the pregnancy) with CMV have little chance of passing the virus on to their unborn child. Approximately 1 in 150 children are born each year with a congenital CMV infection and approximately 1 in 750 children develop permanent disabilities due to this infection. Presently, there is no treatment for CMV but early detection of a congenital infection could lessen the severity of the disability. Children at increased risk should have their hearing and vision tested regularly. This will ensure that children with delayed hearing and/or vision problem will have the best chance to develop to their potential.

Julie also announced that there will be an EHDI conference at the Omni Severin Hotel in Indianapolis on May 11-12.

-Finally, Bob Bowman introduced the topic of using neonatal bloodspots for research purposes. The ISDH has been approached by individual researchers concerning the possibility of using the neonatal bloodspots from the NBS for research purposes. In June of 2004 Dr. Quaid had started researching the ethics of using bloodspots for research purposes. She sent surveys to all 50 State Departments of Health and compiled a formal summary of her results. In her summary, she made the following recommendations:

1. The Indiana State Department of Health should adopt a policy for the use of neonatal blood spots in research, including research priorities in the state that would make use of these samples.
2. Written guidelines should be developed for researchers that explain the policy.
3. Collection, storage and cataloging of samples should be standardized in such a way that the samples have maximum utility for research.
4. The state should adopt the policy of requiring written informed consent for screening that includes the use of the samples in appropriate research.
5. These materials should indicate that the sample becomes the property of the state and may be used in research without personal identifiers unless the parents object in writing.
6. Protocols should be developed for obtaining consent for any studies that intend to use identifiable samples. .

7. All studies must have the prior approval of an Institutional Review Board and should comply with all federal regulations regarding research with human subjects

Following this there was a 15-minute break.

Dr. Bader called the meeting back to order and asked for the Genetics Clinics update. Dr. Bader (Parkview), Dr. Zunich (IU Northwest) and Dr. Weaver (IU Indy) gave reports for their clinics and Bob Bowman gave a brief summary of St. Vincent and St. Mary's in Evansville.

Stephanie Cohen then spoke on Genetic Counseling Licensure. She handed out a document outlining the benefits of licensure for the public, assuring that genetic counselors be qualified for the information they provide to patients and be held accountable if inappropriate care is provided. Formal recognition of genetic counselors via licensure will allow the public to gain access to the valuable services provided by making this group of trained professionals eligible for reimbursement.

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The subcommittees reported.

Joel Conner, chairperson of the Birth Defects Registry subcommittee, reported on the evaluation systems being designed for the collection of birth defects data. He also mentioned how the subcommittee was working to improve the IBDPR and to develop procedures for dealing with outside investigators requesting IBDPR data.

Dr. Weaver, chairperson of the FASD Prevention Task force, reported that the task force is working towards reducing the number of children affected with fetal alcohol spectrum disorder in the state of Indiana. Their goal is to educate healthcare professionals, educators and women of childbearing age about the dangers and adverse effects of alcohol use during pregnancy. This committee is currently looking at grant options to help fund the endeavor.

Krysta Shutske, co-chair of the educational committee handed over the position to Karen Barnett. The educational committee is hoping to sponsor a "DNA DAY" next April 2007, to promote genomic awareness in Indiana.

The next meeting has yet to be scheduled. Two dates have been suggested; October 10, 2006 and October 24, 2006. Regardless of the date, the next meeting will be held at IUPUI. Please email your choice to Bob Bowman.

Respectfully submitted,

Brenda Young